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Drawing from what they know

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Summary

Introduction

Access to affordable and quality health care is problematic for most citizens in sub-Saharan Africa as health systems in this region face many constraints in the provision of health care services. Additionally, health systems now have to respond to an emerging burden of chronic, non-communicable diseases which, according to projections of the World Health Organisation (WHO), will become the most common causes of death in sub-Saharan Africa by the year 2030. The problem is that health systems in sub-Saharan Africa are not yet sufficiently equipped to prevent and manage such diseases. Their primary orientation is on the delivery of acute and episodic care to patients with infectious diseases, whereas diseases that are chronic require health system capacity to monitor, treat and provide ongoing care. The good news is that health systems planners and strategists in the region do not have to return to the drawing board. International agencies, such as the WHO and UNAIDS, and scholars point to the accumulated experience of health services with the establishment and implementation of lifelong treatment, care and support services for HIV-infected patients, which can be used to re-orient health systems and serve patients with non-communicable diseases.

Many factors have shaped how HIV and AIDS has been managed in sub-Saharan Africa. Global prioritisation of the disease has supported experimentation and innovation in the treatment, care and support of HIV-infected patients, since the first case of AIDS was discovered thirty-five years ago. The introduction of national anti-retroviral treatment programmes in the early-mid 2000s in most sub-Saharan African countries allowed the region to begin to view HIV infection as a manageable, rather than as a fatal disease and to act accordingly. During the last decade, sub-Saharan African countries have made tremendous progress in decentralising this treatment to primary health facilities and in establishing care and support networks within communities. How the capacities of health systems have expanded over time to serve the acute and long term treatment and care needs of patients with HIV and AIDS, in the context of resource constraints, provides knowledge of what adaptations have promoted accessible, affordable HIV-related services, and improved the quality of those services. As importantly, that knowledge provides insights into how health systems can serve the growing number of patients with chronic, non-communicable diseases, as well as the long term treatment needs of millions of HIV-infected patients.

The aim of the thesis is *to increase the understanding on how health systems in resource-constrained settings respond and adapt to new health care challenges*. The thesis examines this process of health system adaptation and transition, particularly since the early-to-mid 2000s when anti-retroviral treatment became available in public health services in sub-Saharan Africa. The focus is on adaptations at the level of primary health and community care. The rationale is that research and medical practice literature encourages the management of

chronic conditions at primary health care facilities and within communities; in the latter instance, the bulk of chronic care actually takes place outside the health facility, whereby patients manage their own condition (e.g. by taking their medication on time) with the support of family members, friends and neighbours.

Theoretical background

The thesis draws on complex adaptive systems and system innovation theories for analysis of how health systems respond to new health care problems and how service innovations (and reforms) are adopted or not by all the different actors and subsystems that form part of a health system. Both theories postulate that changes in a health system result from multiple interactions between different actors within and beyond that system, and the intended and unintended influence they have on each other. System innovation theory refers to the changes as 'health system transition' when innovations fundamentally change existing routines in a health system.

The thesis also draws upon two theoretical models on chronic care: the 'Chronic Care Model' by Wagner and the 'Innovative Care for Chronic Conditions Framework' by the WHO. Wagner's model has been widely used in high-income countries. It emphasizes the delivery of chronic care by professional health care teams who actively interact with their patients. The WHO framework is a modification of the Wagner model, directed for use in low- and middle income countries. It emphasizes the involvement of community and family members in chronic care. Both models incorporate patient-centeredness and the delivery of a continuum of care, which are considered important characteristics of chronic care services.

Chronic care takes places at all three levels (primary, secondary and tertiary) in a health system, depending on the care needs of patients. As chronic conditions persist over time, primary level care is generally considered to be in the best position to prevent and manage these conditions within a health system. In order to understand how the different levels and actors involved in chronic care are connected, the thesis refers to the concepts of integration, co-ordination and integrated care, using a framework of Dutch scholars. The concept of chronic care, and within that the delivery of 'integrated care', have been defined and shaped largely by practices in high-income countries due to their earlier experiences of demographic changes (e.g. ageing populations; urban lifestyles) and epidemiological changes (e.g. rise in non-communicable diseases associated with ageing populations and urban lifestyles). Consequently, the thesis recognises that it engages with theoretical concepts which are of limited use currently for studying the development of chronic care in sub-Saharan Africa, and it uses empirical evidence to draw attention to these limitations. Furthermore, the significant theoretical contribution

of the thesis is its proposition of an 'African' model of chronic care to inform empirical studies of primary health care in sub-Saharan Africa.

Research design

The central research question in the thesis is:

What adaptations have occurred at primary health and community level in sub-Saharan Africa to provide long-term treatment, care and support to patients with HIV and in what way do these adaptations contribute to the realisation of a chronic care subsystem within national health systems?

The central research question is subdivided in the following sub-research questions:

1. How have HIV and AIDS community home based care programmes in sub-Saharan Africa evolved in response to the implementation of anti-retroviral treatment programmes and subsequent changing needs of their patients?
2. What has been the influence of HIV and AIDS community home based care programmes on the delivery of primary health care, and the influence of primary health care policies and strategies on HIV and AIDS community home based care programmes?
3. How are primary health and community level services being connected to enable the delivery of comprehensive services for patients with HIV and other chronic conditions?
4. To what extent are existing models of chronic care being applied in sub-Saharan Africa and are they appropriate in contexts of large-scale HIV pandemics and health system resource constraints?

The research used an emergent design in which exploratory studies formed the initial basis of the research framework, whilst insights from the literature and preliminary analysis of field data guided the operationalisation of the research questions. The research questions were addressed in a systematic review of the literature and in case studies. The case study approach was used to collect data on the adaptations and changes made at primary health and community level to enable provision of chronic care. This is an approach which is applied in social science to obtain an in-depth understanding of a complex phenomenon in a real-world context. It included a case study in Zambia, called the chronic care study, which was embedded in a multiple case study covering four countries, and called the multi-country study. The aim of the chronic

care study was to examine the theory and practice of chronic disease management in one country, addressing sub-research questions 3 and 4. The multi-country study examined the adaptations at primary health and community level and the connection between community home based care (CHBC) programmes, national primary health care strategies and providers, as formulated in sub-research questions 1, 2 and 3. In this study, mixed methods were used to obtain information from a range of respondents.

Chapter 4 presents the findings from the systematic review of the literature on self-management interventions for patients with chronic conditions, including HIV. The rationale for this review was to assess the relevance of the research evidence on self-management in chronic care for the design and implementation of chronic care programmes in sub-Saharan Africa. The review considered controlled as well as uncontrolled studies such as pre- and post test studies and descriptive studies. To be included in the review, studies had to assess, on the basis of primary research, interventions to promote self-management in patients aged 18 or over with a chronic conditions. Only interventions delivered by health care teams, community partners, patients or families qualified for inclusion. The review covered 52 studies which fitted the review's eligibility criteria. The review revealed a general lack of literature on self-management interventions for people diagnosed with HIV. It also revealed that self-management interventions yielded very variable results, the pattern being significant changes in specific indicators of patients' health and emotional status, behaviour and health care utilisation but not across all outcomes. There was a general lack of longer assessment periods in the reviewed studies, which was remarkable in view of the long-term nature of the conditions studied. The review also found that most self-management interventions presumed health professional-led interventions, which would not be feasible at large scale in low-income countries given their acute personnel shortages. The review did not reveal any studies on community or family-led interventions, even though chronic care models, such as that of the WHO, emphasise their important role in chronic care. Therefore, the chapter concludes that there is little evidence at present, to inform the design of self-management interventions for chronic care programmes in sub-Saharan Africa in general, or for HIV-focused programmes in particular.

Chapter 5, 6, 7 and 8 present the findings from the case studies. The research methods which were deployed in these studies included an online survey, desk review, semi-structured and structured interview, focus group discussion, service observation, community mapping and a questionnaire survey. The sample sizes per method are listed in table 3.2 of this thesis.

Chapter 5 narrates the history of community home based care programmes in Zambia from 1985 to date. It describes the ethos and practice of community participation in health care, as facilitated by civil society organisations, and the associated process

of developing primary health care (PHC) services in the country. It shows how the form and content of home based care has changed over time and now, together with decentralised anti-retroviral treatment services, represents a local model of chronic care. This provision of chronic care is, however, under threat. The chapter draws attention to government and donor interventions, since 2010/11, which are changing the nature of the relationship between communities and PHC medical staff. It refers to the process of ‘medicalisation’ whereby the broad scope of CHBC services is being narrowed down to treatment adherence on the basis of restricted funding and whereby volunteer caregivers have become quasi-authorities who monitor treatment intake of patients and for which they are answerable to PHC clinics. Furthermore, the government’s efforts to improve PHC services via state-employed community health workers signal movement away from a PHC system reliant on community caregivers towards one that is run by medical personnel. The chapter discusses the methodological limitations of the way in which the government engages with communities vis à vis their envisaged integration of health and social welfare and presence of CHBC programmes which have demonstrated how to empower people to take responsibility, collectively, for their health. The contention is that Zambia risks losing the ground gained in turning HIV into a manageable disease and in establishing chronic care services if the critical brokering role of CHBC programmes is not acknowledged and supported.

Chapter 6 discusses the adaptations in the Zambian HIV programme and how the Zambian government is leveraging its existing HIV service structures to build NCD services. It describes how funding as well as technical assistance enabled the establishment of the country’s first chronic care programme in which different experiments (e.g. use of simpler technology, task shifting, electronic recordkeeping, patient triage) took place. The decentralisation of treatment services, coupled with the government’s commitment to revitalise PHC, has resulted in the delivery of a comprehensive package of health promotion, prevention, treatment and monitoring for patients with HIV at primary level. The chapter highlights the extensive co-ordination of activities of medical staff at PHC facilities, community agents, such as neighbourhood health committees and community caregivers, and managers of NGO-led community health and social welfare programmes. This co-ordination enables patients and families to access medical care, economic, spiritual and social support as part of a continuum of care. There are clear indications that the Zambian government intends to use this foundation to serve patients with NCDs. While interviews with a range of senior health officials did not indicate use of any specific theoretical model on chronic care, it is possible to discern elements of the Wagner and WHO model in their plans. These plans focus foremost on developing capacity at higher levels in the health system. The chapter explains that the different intentions and efforts in Zambia do not guarantee a successful transition of the country’s health system. The outcomes of the re-orientation process are uncertain. On the one hand, there is currently little scope for informed decision making in view of

a lack of evidence on the NCD disease burden in the country. On the other hand, there is also inadequate funding at present to decentralise NCD service technology and skills to the primary level as well as for CHBC programmes to complement this with their wide range of care and support services at community level.

Chapter 7 looks at the broader context in which the Zambian health system operates and implements its policies and strategies. It analyses past and current efforts in Zambia to provide equitable health care since the country gained political independence in the 1960s. Equitable health care, also referred to as universal health coverage (UHC), is expected to take a prominent place in the post-2015 global development agenda. It discusses this agenda in the context of new health care demands arising from patients with chronic conditions. The chapter shows how UHC, under different guises, has been a long standing aspiration in Zambia. It is an aspiration which was severely hampered in the past, for instance by macroeconomic policies, but in the last 6-8 years has been enhanced by innovative strategies in the health sector. This includes the most recent reform whereby primary health, social welfare community development departments have been aligned under one Ministry, thereby re-emphasizing commitment to address the social determinants of health. This chapter argues that this is an important but insufficient step to resolve the underlying social and economic inequities in Zambia which aggravate the burden of disease. The trickle-down effect of Zambia's positive economic growth has been negligible, leaving health and social welfare systems to confront only the symptoms of inequitable economic development and with limited resources. The analysis indicates that Zambian policy-makers are being forced to choose between spreading the available resource thinly or prioritising a number of diseases. Both options constrain the equity agenda. Consequently, it is predictable that the goal of UHC will remain elusive. Much depends on the extent to which the actions of the Ministry of Community Development, Mother and Child and the Ministry of Health are supported by equivalent innovative policies and programmes in ministries that focus on economic development.

Chapter 8 describes how the governments of Ethiopia, Malawi, South Africa and Zambia are seeking to incorporate CHBC programmes into their PHC revitalisation strategies. The chapter puts this in historical context. It narrates the evolution of civil society-led CHBC programmes within the countries' health systems and discusses the prospects for these programmes to expand PHC services as new health care demands arise. In all four countries, CHBC programmes diversified their services in response to the changing health and social care needs of patients on lifelong, anti-retroviral treatment and there is a general trend to extend service delivery beyond HIV-infected patients. Anti-retroviral treatment programmes have led to firmer referral linkages between CHBC programmes and health facilities in the four countries. South Africa, Malawi and Zambia formalised the position of CHBC programmes in their respective health

systems via legislation but this was not the case in Ethiopia (in 2013). The common route in all countries is to make PHC facilities the focal point for management and state-paid community health workers responsible for supervising all community health-related activities, including those of civil society-led CHBC programmes. There are differences between countries with regard to the mechanisms for co-ordinating community health and social welfare activities. Malawi and Zambia seek to join health and social welfare at PHC level and deliver 'integrated care', whereas Ethiopia and South Africa opt to keep these two systems separate. The chapter concludes that CHBC programmes have been a critical resource to the public delivery of primary health and social welfare services in Ethiopia, Malawi, South Africa and Zambia, through facilitating diversification of services and inclusion of patients with chronic conditions, other than HIV.

Conclusions and discussion

This thesis examines the process of health system adaptation, following the provision of anti-retroviral treatment for HIV patients in four sub-Saharan African countries: Ethiopia, Malawi, South Africa and, in particular, Zambia. This is a pertinent analysis in view of the emerging burden of chronic, non-communicable diseases in the region and the concerns about health system capacity to address this new health care challenge. The thesis shows how local home care initiatives developed into distinct CHBC programmes. Global level influences, such as the Alma Ata declaration on PHC and the priority funding for HIV and AIDS, and country level recognition and regulation supported the development and expansion of these programmes. Initially, CHBC programmes occupied a niche position and, over time, they became part of the regime of structures, culture and practices which accelerated access to anti-retroviral treatment and established the institutional capacity to provide chronic care for HIV patients. The thesis draws attention to the many innovations and valuable lessons from CHBC programmes and vertical HIV programmes, which permeated through the health systems of the four countries and which have been components of their efforts to revitalise PHC. In the case of Zambia, these lessons now underpin the country's health system re-orientation process. The thesis discusses the pathways that each of the four countries are using to connect primary health care teams and community-level providers. They all seek to bring health care as close to the people as possible, but do not follow the same paths. At policy level, their pursuit for 'integration' is significant because it underscores their acknowledgement of the vital role of community partners in health and social welfare services and is a clear attempt to leverage in-country capacity for HIV treatment, care and support for broader purposes. However, as the thesis also shows, the redefinition and reorganisation of CHBC programmes could inadvertently erode their potential to be a platform for addressing the growing burden of NCDs and co-morbidities.

The thesis assesses the WHO framework on chronic care on the basis of empirical research and one outcome is the presentation of an 'African chronic care model'. The model emphasises the existence of community partners, their particular form and roles, and the substantive practice of patient self-management in CHBC programmes. The model is different to those commonly used in high-income countries and from which the WHO model was derived. In sum, the research for this thesis suggests there is a nascent, contextually appropriate form of chronic care emerging in sub-Saharan Africa.

The theories of complex adaptive systems and system innovation were used to frame and interpret the research findings. A key feature of both theories is recognition that the actions and interactions of different agencies pull health systems in different directions, such that health system adaptations are not necessarily effective in terms of improving access to, and the delivery of health services. However, this thesis reveals that African health systems are adapting, generally effectively, to the complex health challenge that is HIV and AIDS and using that experience to address other existing and new challenges. The thesis emphasises the critical role of civil society organisations and CHBC programmes in this process. It draws attention to the threat to effective health system re-orientation if their role is not appreciated whilst also showing the capacity that currently exists for developing chronic care subsystems which can enable equitable access to affordable and quality health care in sub-Saharan Africa.

